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Social Media and Austerity: Online Peer Support in Mental Health Communities: Project Final Report

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TABLE OF CONTENTS

1. EXECUTIVE SUMMARY
2. AIMS AND OBJECTIVES
3. SUMMARY OF FINDINGS
4. METHODS
5. DATA ANALYSIS
 - 5.1 DATA SOURCE
 - 5.2 ANALYTIC APPROACH
 - 5.3 CONTENT ANALYSIS
 - 5.4 PHRASE ANALYSIS
 - 5.5 NETWORK ANALYSIS
 - 5.6. CO-WORD ANALYSIS - ‘THE ELEFRIENDS DICTIONARY’
 - 5.7 QUALITATIVE ANALYSIS
 - 5.7.1 ONLINE PEER SUPPORT
 - 5.7.1.1 LOCAL MIND CENTRES
 - 5.7.1.2 PEER SUPPORT - SUMMARY
 - 5.7.2 AUSTERITY
 - 5.7.2.1 AUSTERITY AND THE NHS
 - 5.7.2.2 AUSTERITY - SUMMARY
 - 5.7.3 CHALLENGES (‘ELE-ISSUES’)
 - 5.7.3.1 CHALLENGES - SUMMARY
 - 5.8 ANALYSIS OF REMAINING INTERESTS
6. NEXT STEPS
7. ENGAGEMENT AND IMPACT
8. ADDITIONAL OUTPUTS
9. DISSEMINATION
10. FUNDING
11. REFERENCES
12. APPENDICES

1. EXECUTIVE SUMMARY

This project focused on the role that social media can play in shaping mental health communities in a culture of austerity. Mental health services (NHS and third sector) are facing significant funding cuts, and digital technologies are increasingly being recruited to try to ‘fill the gaps’ left by reductions to physical services. This project aims to identify some of the consequences of increased digitisation of mental health care and support, through investigating users’ peer support practices on one of the first major UK mental health digital media initiatives, Mind’s peer support website www.elfriends.org.uk. The project is a partnership between Universities of East London and Roehampton and the mental health charity Mind.

2. AIMS AND OBJECTIVES

The central aim of this project was to highlight some of the impacts of social media on peer-support in mental health communities across the UK. The original proposal set out to:

- Identify the cultural practices of online peer-support in mental health communities during austerity.
- Produce detailed understanding of service user knowledge, experience and preference with regard to peer-support, and its impact on well-being and resilience.
- Further develop partnerships between the project team, Mind, service users, CCN+ members and related digital technology-mental health initiatives to produce guidelines and strategy for future policies and practice.

3. SUMMARY OF FINDINGS

We have gained significant knowledge of the nature of peer support on Mind’s peer support social media site, Elefriends (www.elfriends.org.uk). We have learnt how peer support works in and through Elefriends, and how this relates to offline support. We have also developed productive working relationships with Mind, and connected the findings to other digital mental health initiatives in the UK. The findings demonstrate how significant austerity is as a shaping force on practices of peer support online and offline. People’s presence on Elefriends is often the result of reductions in opportunities for offline support. People also frequently use Elefriends to ask for advice regarding accessing mental health services that are under severe financial pressure, and are consequently having to adjust their provision.

We found that Elefriends provides a space that in some ways can replicate how peer support appears to work offline (e.g. development of close knit communities of friends). In addition its presence as an easily accessible (i.e. 24/7) online site often created in users a sense of continual

support, of always being there (which differed to offline support). However, the findings also highlight how Elefriends appears under considerable pressure to support people who are facing reduced and/or difficult to access mainstream mental health care. As such, Elefriends is not fully operating as a supplementary form of peer support (as it was designed), but has to cope with people being regularly on the site who need a wide range of support (e.g. crisis intervention), which they are struggling to find through offline services.

4. METHODS

The data collection consisted of two parts - online data collection from actual conversations in Elefriends and a separate set of interviews with members of Elefriends. The aim was to give a good overall sense of the experience of using Elefriends by looking at the things that people say on the site while also asking them directly about how they feel about using it. The online posts were first collected, with online posts and comments being gathered from 157 Elefriends users over a three month period. After that, 26 Skype interviews were subsequently conducted. The findings below discuss the key issues that originate from both data streams.

5. DATA ANALYSIS

5.1. Data Source

A dataset was collated from the posts and comments ('cases') of Elefriends users who had given informed consent for the content of these to be collected and analysed. Data was collected over a three-month period from March to June 2014. In total, this amounted to 38467 cases from 157 users. Raw data analysis revealed this consisted of a total of 1,164,547 words, of which 27,971 were unique. These were arranged in 102,304 sentences, averaging 11.4 words per sentence and 30 words per case. Given the size of the dataset a software based approach (QDA Miner + WordStat) was utilised to categorise the data prior to qualitative analysis, using approaches based on Content Analysis.

5.2. Analytic Approach

We drew upon digital research methods from the emerging field of digital sociology to allow for some initial categorisation of data. Single word content analysis is useful for providing a surface level representation of textual nature of datasets, but does lack substantive context in terms of words and word use (e.g. relating single words to specific categories). For this reason we explored the use of more sophisticated content analysis, namely phrase analysis, and co-word analysis. Phrase analysis focused on frequency of a set number of consecutive words, and co-

word identifies the most significant associated pairs of word based on frequency and proximity. This approach emanates from early Science and Technology Studies, which investigated key issues in scientific abstracts (Callon et al., 1983). To date, co-word has been mostly frequently used to analyse small sections of data (e.g. Twitter posts). Our project was focused analytically at the level of the ‘case’, which relates to individual posts and comments. As such we treated ‘cases’ as the analytic unit, in the same way that Marres & Gerlitz, 2014) analysed Twitter posts. In using phrase and co-word analysis we aimed to overcome the issues associated with pure single word frequency analysis, particularly in relation to citation analysis. The idea that they can be used to identify current ‘live’ issues has made them particularly attractive to some forms of digital social research, e.g. Twitter (see Marres & Gerlitz, 2014). Our requirement to analyse how support ‘operates’ in Elefriends, resonates with the concerns re ‘liveness’ of other forms of digital data in the growing field of digital sociology. We were focused on identifying the multiple ways that support works in Elefriends, and in such a way that does not rely on measures of single word frequencies. The sheer amount of posts and comments in our data set made the use of such a technique essential.

Undertaking this approach meant that our project came to involve a partial ‘redistribution’ of social research (Marres, 2012) towards the technologies themselves. In this case, the research methodology became significantly shaped by the nature of Elefriends (e.g. format of posts and comments). For example, a larger than originally planned participant sample was gained as the ethical procedure for recruiting participants had to be embedded in the site itself. This was done through a series of comment boxes through which the Ele (the animated Elephant character on the site) introduced the research team and nature of project. Users could ‘click’ through each stage if they wanted to find out more information, and finally to provide consent. Recruitment was very quick, and as such the sign up process remained ‘live’ beyond the point when 100 users had joined the project. We did not want to exclude any user that had signed up (as we felt this would have been unethical) so we ended up with 157 participants for the online data collection stage. This demonstrates the role of the technology itself in the research. Moreover, it involved interactions between the researchers, Mind and their tech developers that facilitated the embedding of ethical procedure into the Elefriends site. In this sense, the research was (re)distributed across a number of stakeholders (academic, charity and IT sectors). Our approach sits within broader debates about the impact of digital technologies on social research (e.g. what methods are needed to analyse ‘big data’) and the comparisons between quantitative and qualitative approaches (Marres, 2012). Our response to this was to incorporate quantitative forms of textual analysis (e.g. phrase and co-word analysis), that could provide analytic insight into patterns in the data as a whole, as well as inform areas for subsequent qualitative analysis. In this sense, the project was very much a mixed-methods approach.

5.3. Content Analysis

The most popular word in the dataset, once general terms were removed, was the word ‘hugs’ (appearing in 284 instances in a random sample of 2,500 cases). This is perhaps explained by the way that many users of Elefriends will close a conversation with the word ‘hugs’. The table demonstrates that the top three words on the site are ‘supportive’, and indicate how the primary function of the site is to provide emotional support in terms of helping people live with on going forms of mental distress. As we will see in the analysis that follows, the words ‘hugs’, ‘hope’ and ‘feel’ are central discursive parts of the ways that support works on the site, both in terms of providing and seeking support from other users. Along with ‘love’ and ‘xxxx’ we see that 50% of the most frequent words are related to making Elefriends and warm and supportive place to be.

Table 1. Netyltic

Term	No. Instances
hugs	284
hope	270
feel	237
today	219
time	195
really	187
going	182
love	181
they	162
xxxx	150

5.4. Phrase Analysis

We then completed a phrase analysis (He, 1999) of the data, through the Wordstat software programme, to add some context to the word frequency data. A phrase is defined as a number of words occurring consecutively in a sequence. The first of these examined long phrases (4-7 words - Long Phrase Analysis), as these have the best chance of being properly representative of actual phrases. The second expanded the scope of the search (2-7 words - Wider Phrase Analysis) to include smaller phrases that may have been overlooked by the restrictions of the first analysis. Figure 1. gives a good indication of different phrase clusters, many of which relate to support in various ways. These can be broadly categorised as seeking support (e.g. "I don't know what", "I don't want to", "I don't know how", "I wish I could"), offering support (e.g. "How are you" in various forms, "Been thinking of you"), receiving support (e.g. "Sorry to hear that", "Always here for you", "Hope you are OK", "Take care of yourself") and gratitude for support

This initial phrase analysis demonstrates that there is a considerable amount of support provided through Elefriends, as well as gratitude for that support (e.g. Thank_you_so_much). The most frequent and significant activity on the site involves textually setting the conditions for support to take place. The phrase analysis demonstrates that the support on the site is predominantly positive, and the Elefriends community can be seen to be very supportive.

5.5. Network Analysis

A network analysis was completed on the data by mining the dataset for user names in the messages. This identifies the connections across all messages and graphically represents those members who have had communication across the network. Figure 4 shows the network of the unique names in the current Elefriends dataset. It is not a complete picture of all the users in the network as representation is based on users who actually mention another member in one of their messages. Figure 4 shows that the central node is 'Elefriends' and means that members tend to speak of Elefriends and many of the other members of the community. This relates to the importance of 'Elefriends' as a figurative term, which can then be drawn upon by users to create a sense of connection across the online community. For instance, users often referred to providing a supportive 'trunk', using their 'trunk' to 'water the seeds' of support, and 'flapping their ears' in support of other users. This is in addition to the general trope of referring to each other as 'eles'. This is clearly a close network of people who regularly speak to one another via Elefriends. Figure 4 also shows that there are a small number of people who only speak to a discrete number of people in Elefriends as shown by the connections at the edge of the network that do not mention the wider community as frequently. This is interesting as it suggests that although posts on the site are visible to all users (which at the time of writing is approx 18000), the actual networks of on going support tend to be quite small. It also matches the findings from the interview data that identified how some people choose to speak to the same people every time they visit Elefriends.

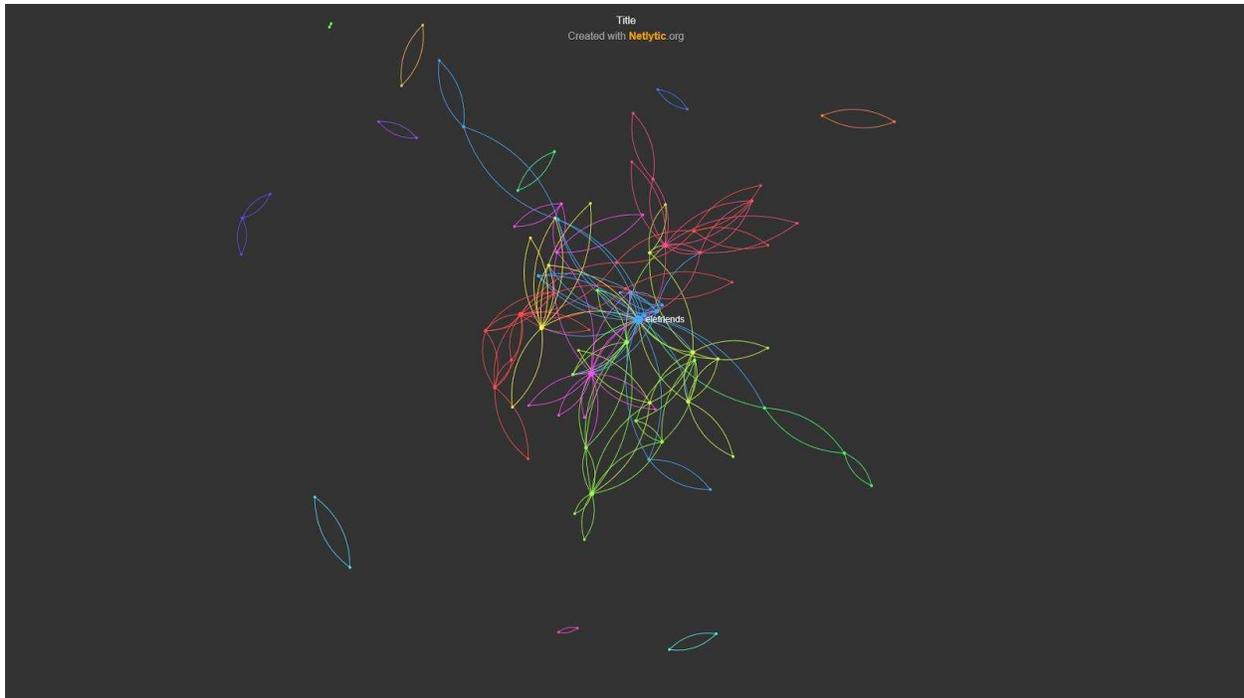


Figure 4.

5.6. Co-word analysis ‘The Elefriends Dictionary’

The next stage of analysis was co-word analysis on categorised data. This involved an initial ‘creation and validation’ stage, which allowed for the classification of text with regard to a user defined dictionary of words. It was necessary to create a custom dictionary to allow for examination of some areas (e.g. AUSTERITY), whereas other areas allow for coverage by reference to specific keywords (e.g. ELEFRIENDS). Categories reported in the specific analyses have all been validated using Key-Word-In-Context (KWIC), which allows specific items of interest to be extracted from the dataset, to ensure these accurately capture the concept being categorised. Words that were properly representative of a category at least 80% of the time were considered valid. The KWIC feature of Wordstat allowed us to mine the dataset, following initial categorisation, for extracts that we analysed qualitatively.

5.7. Qualitative Analysis

Specific analyses were undertaken to investigate the main categories of interest. Unlike the general analyses, these methods can be said to be ‘interested’ (Marres & Gerlitz, 2014). This stage of the qualitative analysis will primarily use thematic analysis to explore the data. Thematic analysis involves looking at the topics or ‘themes’ that appear in a narrative. Analysis is conducted by working through the data, usually line-by-line, in order to identify the key themes

in the data. Braun and Clarke (2006) argue that thematic analysis works to reflect reality and to unpick or unravel the surface of reality. As with many other qualitative methods, thematic analysis requires a thorough examination of the data and requires being fully immersed in the data. The Elefriends data will be examined in terms of three key themes: online peer support, austerity and challenges. We will be examining data from both the online data and the interview data.

5.7.1. Online Peer Support

The term ELEFRIENDS was used to investigate peer support, having also appeared frequently in both the Austerity and Local Mind analyses. A KWIC search was undertaken to investigate how users were using the term ELEFRIENDS in relation to aspects of peer support. These were separated into various recurring themes, each of which provides valuable insight into issues regarding peer support and how Elefriends is used. This shows us that peer support (via the Elephant) features in a high proportion of the conversations recorded. Let us begin with some examples:

"I just had cause to remember what life was like before I found elefriends. I had had friends who knew about my s[elf]h[arm], but I'd lost them all, through my own stupid actions. I was totally without anyone before I found this place. Thank you. All of you xxx"

"Hi, that's what Elefriends are for, a place to express your self , openly, without judgement, but support and understanding, keep posting , take it one step at a time, big hug XXXXX"

"I'm honest on here and I don't worry about sounding weird or feeling sorry for myself or bonkers. I'm just me on Elefriends xxx"

".....Have received some bad news tonight, a close and dear friend of my family died this afternoon, got a call tonight. - this is where i have to say, that i find ELEFRIENDS invaluable, a place i can come to and when i explain/tell how i am at that very moment in time, there will always be someone there. - i have found this to be of a huge help to me and support."

"I was a bit tentative at first because I didn't really know what to expect. I felt odd, because there's, like, no security and there seems to be a lot of chat, like, anyone could be anyone. Even though you'd presume that everyone on it has something in common –

The above quote shows that people refer to Elefriends as a ‘sacred’ community and how they are always interested to meet new people. Given the fact that Elefriends continues to grow, it can still produce a sense of close-knit community. There is also evidence in the above examples for members of Elefriends meeting up offline. This shows that community has the potential to extend beyond the boundaries of the online environment and that people are able to make friendships that can continue into offline settings. However, it is perhaps more likely that the majority of connections are based solely on the Elefriends site. As with earlier extracts, there is a strong sense of the close connections in Elefriends so much so that one member describes them as ‘family’. Elefriends users are like a family as they provide networks of affection that can be instantly called upon at a time of distress. The following quotes also explore how people have turned to Elefriends at a difficult point in their lives:

"Good morning Elephant!! I just wanted to pop on by to say a MASSIVE thank you for everything you do!! You've provided me literally with a lifeline - I don't think I'd be able to cope if I didn't have this wonderful place to turn to. I've never known anywhere to have so many special, kind, big-hearted & wonderful people in one place. I'm eternally grateful for finding this place. You & your Ele-handlers do such a wonderful job of looking after us all. I find it hard to be able to express how I feel but I hope this goes a little way to show how thankful I am. Love & hugs to Ele & the Ele-handlers
XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX"

"Would not still be here without the Elefriends it is as simple as that"

So far we have seen many instances of users reporting positively about the support they feel Elefriends provides to them. In addition to this it is important to note the many instances in which users stated that having Elefriends available to them had been potentially life saving. It is clear that for many people who were at risk of self harm (and potentially suicide) that having Elefriends to harness support through has acted as a significant de-escalator of risk. This is a significant finding and one that supports moves to develop the scope of its use. This finding is also echoed in the interview data:

“Yes. I’m not very good at seeking support, but I use it like to prevent, I suppose, and just – more as like a cheering squad if I’ve got thing to do or if I— Quite often, if I have to leave the house to go somewhere I post something and then loads of Eles will come on and give you encouragement and that’s quite nice. Or I’ll ask for hugs or there’s been a couple of times when I’ve been quite close to taking an overdose. I think people were really good at that time. Kind of keeping me out and (lon[2] g pause) yeah there’s lots of different levels of support. (laughs)” (Int. 7)

This level of support is considered to be always ready at hand and the following user explains how they do not even need to access their Elefriends account in order to tap into some of the benefits:

"I think the best thing about it, actually, because I access it on my phone, I'll have a – they'll all cheer me on and then I – because even if I don't log in to Elefriends, because I'm carrying that phone with me, it's almost like I'm carrying my cheering squad with me.

(interviewer) (Laughter) Aw, that's lovely.

It's like, "Oh. I've got my Eles in my pocket. I'll be fine." Sometimes the internet won't work, so I can't actually log on, but it feels like they live in my phone." (Int. 18)

The above user of Elefriends describes how they do not even need to access their phone to feel connected to the Elefriends community. They describe how they have the 'Eles in my pocket' as a kind of potential source of encouragement that can be called upon at a moment's notice. They have a 'cheering squad' that they can access at any time. As we can see, the app provides support by just being there and the user does not even need to directly use the app to get a sense of support or encouragement. Simply having the phone to-hand means that the Elefriends community is always close by. Therefore, Elefriends does not directly operate as a source of information but an affective network of potential inspiration. It is always there and it acts as an entry point to alternative ways of feeling.

This shows how support can operate in a purely online form. In the following section we look at how people mention their attempts to access offline forms of support.

5.7.1.1. Local Mind Centres

Mind was mentioned during the phrase analysis, and appeared as a relatively central topic, particularly in relation to conversations on Elefriends about the nature of the offline support users experienced. In the data below we see the presence of close links between offline and online support, with Elefriends frequently used to discuss users' experiences with offline support, particularly local Mind centres. This is clear evidence of the value of Elefriends as a supplementary form of support to existing offline provision. The findings also suggest that at times Elefriends can become the primary source of support, particularly when facing problems with achieving desired level of contact with NHS and/or third sector face to face care.

"Home and had a nice chat with my support worker, nice to have someone to talk to and share an offload on what I was feeling. My support worker is gonna help me find a walking group for me to be active in and also going to find me something else to do as

well instead of attending Mind all the time, I'll be attending my local Mind at least once a week and focus mind on something else. I need to get my life in order for me to achieve things better :-)"

"I find elefriends really supportive and keeps me going, sadly my local mind weren't very helpful they don't offer counselling and charge for all there other services :(I'm sorry to hear that you weren't able to get any therapy from the NHS... I hope you too find this site supportive x"

"Feeling desperate with everything is happening in my life and I feel like I'm not getting the support I need and I can't even get the support from my local mind because they charge! Which is something I can't simply afford"

The comments above show how the users speak about their experiences of engaging with local Mind centres. For many, it is a good opportunity to share positive experiences with other members of Elefriends (such as the first user who mentions the local mind group providing information on a walking group). Elefriends is then a space for encouraging people to connect with wider Mind services and can even, as with the comment above, seem to offer some support when there is a problem with the Mind services (e.g. the difficulty affording counselling services). In this case, the user comments on how they still find Elefriends supportive. This is a good example of Elefriends bridging the gap between face to face and online forms of care.

Attending local Mind services was often recommended as a source of support and was frequently mentioned alongside Elefriends. Difficulties in accessing local Mind centres, either physically or financially, increases the importance of other forms of support as a means of facilitating recovery. Issues surrounding social anxiety may also create problems with access to support during busy periods at local centres. For some users local Mind centres were discussed as providing valuable support, demonstrating how the potential for funding such activities vary by location:

"Hi MIND do rock!!!! I am waiting to start a mind centre and they have soooooo many activities on offer that I was looking for ages what to choose from. I have to have a support worker with me on the days I attend but I am going to be going from 10am to 4pm 4 days a week if I want to. I am also been lucky enough to get funding for me to pay for gym and swimming membership so if you would like that too then your MH team might be able to get it for you. Big moon snuggles xxxxxxxxxx"

5.7.1.2. Peer Support - Summary

The findings illustrate a range of considerations with regard to peer support. Most notably, given the volume of comments expressing gratitude to other users, it seems reasonable to infer that the people using the site certainly get something out of it in terms of support that they find useful. In some instances, Elefriends appear to have met in an offline environment after connecting on Elefriends and given the positive comments alongside these excerpts, have potentially resulted in new (offline) friendships that are likely to be a valuable source of peer support. Other instances echo this, with remarks such as having made "friends for life". The data illustrates a clear sense of community between Elefriends users, the community caring for each other, and sometimes becoming quite attached to both other users and the Elefriends environment. There are differences between how this kind of support differs between online and offline environments, as shown by descriptions relating to 'what Elefriends are for' and the case extract on 'attending a local group'. The majority of instances appear to favour online support, with some expressing desire that their offline environment was more like their online environment; at least with regard to supportive sites such as Elefriends. Facebook was not regarded as a source of support. Elefriends was favoured by people due to the ability to seek support and understanding by speaking freely and openly, in their own time, to express how they are feeling, without apology, to others who have experienced similar feelings; and without being judged or made to feel uncomfortable about expressing themselves.

5.7.2. Austerity

The issue of austerity was central to the project's aims. Whilst it became clear that consequences of austerity shaped a lot of activity of Elefriends, the site was also used to discuss issues users have with existing face-to-face services, and their ideas about how mental health services could be improved. The first aim of this stage of analysis was to gain some descriptive detail of how austerity was being felt in the everyday lives of Elefriends users. To this end, a co-word analysis was run to investigate the categories of AUSTERITY, INCOME and PERSONAL. From the three target categories, AUSTERITY ranked consistently higher than PERSONAL or INCOME. As most representative of the three, a KWIC search was performed on the AUSTERITY category to capture a sense of what was being discussed in relation to other dictionary categories, illustrative quotes are shown below. When specifically discussed on Elefriends the issue of austerity was mostly commonly related to NHS and private mental health services. Most often this was in terms of users feeling that NHS provision was being negatively impacted by funding cuts, which left users feeling unsupported and without the care they need:

5.7.2.1. Austerity and the NHS

"Have you had cbt before or has anyone spoken to you about it ? They generally like to explore that first before dbt to be honest waits are up to two years for dbt and it is very intense. If you have got a good relationship with your family have you considered them help fund a counsellor privately. If I had the money I would, everything is limited on the nhs so it is something I will pay for myself when working just to make sure I stay on track."

"I was disappointed to hear from the instructors that this was the last Suicide Intervention course to be run in our area and the the last Mental Health First Aid course had already run. Funding for these courses has been cut from end of March, although funding for physical health education courses such as drug, alcohol and smoking health awareness continue to be funded. - Mental health support services first in line for cuts again. Depressing."

"thank you [] there is recovery and day light. I want to help those that are suffering as Mind has been fantastic and Elefriends. I want to give back and give hope as the Nhs are useless at doing this and the government, shame on them. xxxxxxxxxxxx"

Elefriends is used to discuss issues with mainstream services. People shared experiences reduced NHS care, and problems accessing support. Explicit mention of cuts in NHS services was often made, as well as suggestions for alternatives. For instance, the 'hole' in care opening due to austerity was often said to be able to be filled by private provision. Whilst for many this was something they desired, it was frequently only a select few that could afford private care. As such it was frequently not a realistic solution to reductions in mainstream NHS services. For example:

"I totally feel for your wife sweetheart. I am currently on a six month waiting list to see a clinical psychologist and they can't do anything else in the meantime. My friend has got herself into debt paying Â£40 per session for a private counsellor cos she said if she didn't she would end up in hospital and I'm thinking of doing the same even though I have no income. It's disgusting and all wrong, anything could happen in the time she has to wait. Sending massive massive hugs, neither of you are alone in this xxxxxxxx"

Not only was Elefriends used as a means to support other users, it was also used to seek specific information from Mind through the site. Such 'ask the Elephant' requests varied in content, and occurred despite the site being clear that it does not provide specific guidance (although it does direct people towards other sources of support as necessary, e.g. Mind InfoLine).

"Hi elephant, I thought id write to you as I'm trying to get therapy, have to wait a while on NHS so thought id try my local mind 'plymouth' I was saddened to hear when I spoke to them that they don't offer any counselling and you have to pay for other forms of therapy.. This made me very sad as it's off limits to me as I can't afford to pay for treatment :("

In this extract specific support is sought from Mind itself, rather than other users on the site. Mind does not provide specific guidance on treatments and therapy, although they do have a telephone Infoline, which moderators can direct such requests to. It is clear from examples such as this that users can consider National and Local Minds to be the same organisation (although the latter actually operate as individual charities with individual funding structures).

5.7.2.2. Austerity - Summary

These extracts show how Elefriends can act as an 'always there' form of support, stable in relation to changing patterns of offline provision. Elefriends is used extensively for people to discuss the organisation and management of offline mental health care, which is often perceived as limited. This exists in relation to NHS care, as well as local Mind centres (although the latter varied geographically). Users become moved to consider private care as a desired therapeutic options but discussed its issues in affordability and concerns are expressed there is no guarantee of efficacy, adding a level of uncertainty and anxiety with regard to seeking private treatment. Austerity also appears to add additional stress in various ways, such as choosing between wealth and health with regard to employment; funding cuts and uncertainty over future funding are also cited as hampering recovery. The Government is seen as prioritising money over people and that it should be doing more to address mental health issues.

5.7.3. Challenges ('Ele-issues')

So far the findings have highlighted the many positive forms of support provided by Elefriends, and how important the site is for people with varying levels of mental distress. Indeed, at times users feel so strongly about the benefits of the site it is reported as lifesaving. However, that is not to say the online environment is perfect, as there are some instances that appear to be causes for concern for those using online peer support. The first of these might be termed 'reactive distress'. This is where comments from others are perceived (correctly or not) to belittle or undermine 'active distress/grievance', resulting in further distress and/or anger at the offending comment/comment poster. Given the emotive and stressful nature of such occurrences it is likely some other users would get involved with trying to diffuse the situation (successfully or not). For others this may act as a trigger of sorts, seeing what appears to be conflict in what they consider a safe space, which may result in people temporarily removing themselves from the online

environment. It may also cause a temporary biasing of support, as if many users are drawn towards resolving the 'hot topic', other concerns may receive less attention. Users having respect towards and understanding of the purpose of the site also relates to this issue, as users not displaying these qualities can be a cause of upset for others. Not knowing what to say as a way of support to other users can also be difficult.

"I'm sorry if I upset you. Your post has been removed so i can't see your reply. I just agree with [] about counting to 10 before posting. Lots of us do care on elefriends xx"

"Elefriends used to be a lifeline for me. Now it seems the relationships I had built are gone. The strongest most meaningful support for me, vanished. What happened? The crisis team are leaving me in Thursday too - Iapt discharged me because I wasn't suitable ... Everything's gone. Why? Why am I unhelpable? The world is making me isolated, just me, the voice & my suicidal thoughts. It's clear to me what is meant to happen. All the help and support is falling away because I'm not supposed to get better, I'm not supposed to get help. Destiny. It's my time. I'm not meant to be saved."

"Oh sweetie, I'm so sorry you feel like this. Your elefriends are still here for you, we haven't gone anywhere! The crisis team discharged me as well but I've since decided that I'm far better off without the stress and uncertainty they caused me anyway. Did they refer you to a community mental health team at all? Are you on the waiting list for anything? You are definitely helpable, it's just that the system is rubbish. It's the same for all of us, so please don't feel like you're being personally victimised because you're not. NHS mental health services are just drastically inadequate, understaffed, and underfunded and we as the patients are the ones that suffer. Please keep reaching out because you're not alone in this and nobody here wants you to come to any harm. *big hugs* Xxxx"

Whilst many users stated they would not want to leave Elefriends, others say they need to leave Elefriends in order to continue their recovery effectively. Having benefitted from online support, these users now feel the need to 'lose the crutches' by taking time out from the site.

"I'm gonna have to break from elefriends. As I'm clearly on here everyday. I need to take it easy with my anxiety too. I might even delete my account to start the break later on. If I don't delete I will never give myself a break that I deserve. Sending love to all ;-)"

"Morning [], it makes sense to limit yourself unless you have the time. I know at first it was so important when i was really poorly. Now things have improved with MH i find it

is important to focus on going fwd which needs time to put in place and energy. I love elefriends, forever but you must always put yourself first. wishing you a fab day xxxxxxxx"

In part, this might be related to the concept of being an 'Ele-burden' or a 'Bad Ele', a concept that is mostly used in self-reference. This may occur if users perceive they have received more help than they have been giving, or self-awareness that their own issues may sound trivial to others, or if they have been absent from the site for some time. Many instances in these categories could be described as having implicitly moral sub-text; relating to care, fairness/reciprocity, and duty/loyalty/respect. The underlying concept, I ought to be able to handle this myself/I should not burden others with my problems, is also inherently moral.

"I have looked back at my previous posts and realise that they have been mainly negative. I am sorry for this but I feel that here on Elefriends is the only place I have at the minute to put all my negative feelings down so that I dont bottle them up and end up doing something silly, like hurting myself."

"Sorry Elefiends for continuing to burden you. I love you all dearly & I hope you're all having more peaceful, kinder & safer day than I am. All my love & hugs to everyone xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx"

"I want to apologise to all of my Elefriends and especially my special friends who have been sending me PM. I have been to hell and back and desperately don't want you guys to feel like you have been forgotten. A big special thank you to the amazing [], [], [], []and everyone one else who has shown me support."

At times when users are expressing a concern in relation to being a burden to others the broader community tend to try to respond positively, reaffirming that the site will support, through thick and thin, and generally reassure that it is okay to have periods when providing support to others is difficult. Feeling a burden is generally not thought of as reason to take a break. Indeed seeking support from others, even at times when it is not possible to reciprocate, is very much what Elefriends is reported to be for:

..."I'm sure most eles go through dry spots where we don't feel up to doing much on the site. Part of the beauty of this place is there seems to be enough elefriends that someone else will be there to help out. Sure they won't say exactly what we would say - none of us are replaceable - but I think there will always be someone to say something supportive. :) "...

"Haven't been on here in a while; had a really bad week and to be honest have been considering S[uicide]. Haven't felt that bad in a long time, but I think I'm slowly coming out of it now. Though, I'm still feeling depressed and anxious, I don't want to end up being sectioned again. Trying to resist curling up forever in this black hole I seem to be in is really hard. I've cried so much this week. Waiting on another letter with an appointment with my psychologist sometime soon, I really hope I can get one. I can't carry on with this burden on my own any more. I feel bad for being such a bad elefriend (If I can even call myself one anymore) I haven't provided anyone any support recently, but I've felt I was simply unable to, because of how bad I was feeling myself. I'm sorry."...

..."Of course you are still an elefriend we all need to protect ourselves every now and then."...

..." Sometimes you have to be your own Elefriend and not worry about being everyone else's."

Other issues also focus on other users responses, but this time a lack of response. For example, users not being acknowledged by others who have previously acknowledged them or finding that others they previously engaged with are no longer on the site. This may lead to a feeling of 'starting again' or being 'beyond help', the latter of which can also occur in isolation and suggests that whilst online peer support is helpful for many people, it does not work for everybody. These issues highlight how Elefriends comes to act not just as a 'technology of care' in and of itself, but comes to co-produce the on going practices of support and care of users on the site. In a sense, Elefriends comes to be part of what needs to be cared for and supported (Schillmeier, 2014). Here we see how online support becomes relational between users and the technology of the site itself. The absence of a user can also be a cause for concern, in that others may worry about them when they are not there.

"I know - have been so worried about her but knowing she was here among safe & loving Elefriends meant I could try to support her :- (Does anyone know anything about [X] deleting her account? I'm just worried she's not safe :- ("

"Every time I stumble across an account that has been deleted I find myself worrying about what could have happened to that person. What if they are not okay? What if I could have helped? Where have they gone? What if I disappear next? How can I find out how they are? Do the Elehandlers check on people? "

"Yeah. I mean it is hard when you've got particular friends. Like one of my friends recently had taken – had been – had taken an overdose and nearly died, actually,

somebody I'm very close to on Elefriends, and that was – and they've been going through a pretty hard time and, you know, they were in intensive care and things like that. So they were quite ill recently and they kind of went offline for a few days. And that was quite worrying, I have to say. So yeah, you do still worry about people. You know, they come back again and they're better again, which is good. But yeah, you do worry about people you have made a connection with. Yeah. It's kind of normal, I suppose. But you hope that the fact that they have got that kind of friendship there, that they will come back.” (Int. 14)

Here we see the one of the main concerns on Elefriends is periods of disconnect, particularly if a user leaves a negative message and then disappears from the site. It is difficult to account for a lack of communication and it appears that Elefriends, while being a great source of inspiration, also presents a new set of difficulties in the way that people care for the other members of the site. Caring for people in Elefriends requires seeing people being active on the site. It is regular for people to take breaks from being on the site – as the above example shows – but these breaks are carefully monitored by the other members of the site and any unexpected distance from the site is likely to encourage a concerned reaction from the community.

5.7.3.1. Challenges - Summary

In this section we have seen some of the challenges facing positive online peer support on Elefriends. The positive aspects of the technology (e.g. 24/7 nature, ability to connect with new friends) have the possibility to also be negative aspects, (e.g. feeling a burden on others, periods of disconnection). Some of these relate to Elefriends being a social media platform (e.g. disconnection disrupting the community), and yet they take on specific importance due to it being a mental health social media platform. On Elefriends, what can be perceived as normal social media behaviour can be perceived to be a significant indicator of risk. It is important to understand that digital technologies do not work in the same way for all communities they are introduced, and as such, specific consideration must be present depending upon the nature of the community under focus. This helps us to remember that the primary question is not ‘how does the technology work’, but ‘how does the technology fit into the existing practices and concerns of this community?’. We need to start with communities and consider how digital technologies can potentially help them, rather than assume the perceived benefits a given technology will be equally felt by all.

5.8. Analysis of Remaining Interests

The initial phrase analysis raised other specific issues that appear to be key issues people seek and provide support for on Elefriends; specifically "trigger warning", "crisis team" and "side effect". These appear to relate to various aspects of care, notably a lack of available services, significant delays in accessing services that are available, disparity between physical and mental health care, and a lack of understanding with regard to mental health conditions. We did not have time to explore these in detail, and plan to explore through follow on funding bid/s.

6. NEXT STEPS

- Complete two journal articles (see dissemination). This will communicate the findings from this project to the academic community. Our participation at recent conferences has shown us that the data gathered from this work will be of great interest to the academic community. Like people working in the mental health sector, academics are keen to find evidence for the benefits of peer support and there is a movement towards the close examination of how social media sites provide a possible space in which to provide mental health care.
- Present findings to Mind. Mind are keen to gather evidence for Elefriends and consider the ways that it might be improved. There are positive messages that can be communicated to Mind (namely, about the benefits of peer support) but there are also some areas that could be improved based on this research (for example, the way that 'Ele handlers' and the members are briefed about the issue of 'deletion').
- Apply for follow on funding to allow for further analysis of online data set in relation to treatment and care. It would be valuable to know more about how people use Elefriends to share 'treatment stories'. This could include looking at the specific references to particular medications and would not require any further data gathering as this issue (and many others) are fully represented in the current data set.
- Present findings, and feed them into discussions regarding future CCN+ plans as part of the Collaborative Futures Annual Event in Leeds in December 2014.
- On a wider note, mental health services are commonly claimed to be in 'crisis' by broadsheet, tabloid and specialist media due to reduced funding in a context of greater demand. There is considerable interest in understanding how digital media tools can help to support people during this time. We aim to disseminate these findings in order to demonstrate the value of online peer support. We aim to disseminate the findings more broadly (e.g. through Mind press releases) to ensure that the value of peer support is understood by NHS Trusts, CCGs and third sector organisations, in addition to the focus on personalised digital tools (e.g. Cognitive Behavioural Therapy mobile apps). We are keen to emphasise the importance of notions of community and sociality in the design and implementation of digital mental health tools.

7. ENGAGEMENT AND IMPACT

- Workshop at MindTech, Nottingham University. MindTech are a NIHR Healthcare Technology Co-operative focused on digital mental health initiatives, and includes staff from NHS and academic sectors. MindTech invited us to run a workshop in November 2013, with members of Mind, MindTech and patients. This was part of their public patient involvement activity (PPI). We used the workshop to present the findings, and to discuss the outcomes in terms of methodological contributions to the field. The patients responded positively to the findings, and MindTech staff are interested in using the findings to inform their work on other major digital mental health tools (e.g. BigWhiteWall).
- We have been invited to a MindTech shared learning workshop in London in January 2015 to advise on a funded evaluation they are conducting on seven Innovation Labs funded digital tools for young people.
- We are aware that Mind have a new major peer-support programme in planning (supported by 3.2 million Big Lottery Funding). The project findings will be presented to Mind so that they can inform thinking regarding the potential use of online peer support through Elefriends in the Big Lottery programme.
- The project has facilitated a strong and productive working relationship with Mind, particularly through the ‘subcontracting’ of Seaneen Molloy-Vaughan, an Elefriends moderator, who was able to very successfully connect us to the Elefriends community through recruitment and user engagement activities, and with Youmee (Mind tech developers) in relation to embedding the informed consent process into the Elefriends site itself.
- Communication of findings to users of Elefriends. A one-page summary of the research findings was put on Elefriends. This gave the community the opportunity to comment on the research findings (Appendix 2). Users that responded reacted well to summary, agreed with the research findings and were proud to have taken part in the project.
- Mind are planning future user engagement activities with Elefriends users. We are in discussion with Mind as to how best to incorporate our findings into their on going user engagement programme. The workshops they run are generally outsourced to an external professional workshop organiser and facilitator.

8. ADDITIONAL OUTPUTS

- The data set: this project has collected a large body of data on Elefriends. The online data amounts to approximately 1.1 million words and although this project was primarily interested in austerity and peer support there is certainly scope for future projects on a range of other topics that could be explored via this data set (e.g. treatment).
- The animations produced by YooMee. These animations were used to communicate the research to the members of Elefriends and encourage them to take part. (Appendix 1). The animations were translated into a language that is appropriate for Elefriends.
- The ethics procedure: The project has developed a model for embedding ethical and informed consent procedures into social media sites, which can be used in future projects.

24

- Specifics of the analysis. There are two main strands to the analysis that both contain outputs. For example, the quantitative analysis includes the textual analytic output, word clouds and a graphic representation of the unique names mentioned in the online data.
- Successful completion of the project with Mind and the possibility of future projects with the mental health charity.
- A working definition of online peer support in Elefriends: **‘Offering peer support means allowing a person to seek support and understanding by speaking freely and openly, in their own time, to express how they are feeling, without apology, to others who have experienced similar feelings; and without being judged or made to feel uncomfortable about expressing themselves.’**
- A research webpage: <http://digitalcommunitycare.wordpress.com>

9. DISSEMINATION

Journal Articles

- ‘Social media and mental distress: Online practices of digital care’ (in preparation). To be submitted to Social Science and Medicine
- ‘Digitally mediated distress: Bodies, affect and digital self care’ (in preparation). To be submitted to Sociology of Health and Illness

Conference/workshop presentations:

- Tucker, I., & Goodings, L. ‘Austerity, peer support, and mental health communities’. Living in the cuts: Policy, politics and everyday lives in the recession. ESRC Novella conference at British Library, May 2014
- Tucker, I., & Goodings, L. ‘Social media and mental distress: Online practices of digital care’, EASST conference: Situating Solidarities: Social Challenges for Science and Technology Studies, Torun, Poland, September, 2014
- Tucker, I. & Goodings, L. ‘Social media and austerity: Online peer support in mental health communities’. MindTech seminar series, Nottingham University, November, 2014
- Goodings, L., & Tucker, I. ‘Digitally mediated distress: Bodies, affect and digital self care’. Concerning relations: Sociologies of conduct, care and affect, Exeter University, November 2014
- Tucker, I., Goodings, L. Raymond-Barker, B., & Molloy-Vaughan, S. ‘Social media and austerity: Online peer support in mental health communities’. CCN+ Annual Event: Collaborative Futures, Leeds, December 2014

10. FUNDING

- We plan to explore the possibility of securing funding from Mind to develop the findings into a larger peer-support project as part of Mind's upcoming Big Lottery funded peer support programme.
- We plan to apply for some follow-on funding from CCN+ to further analyse the current data set, and to explore further user engagement activities.

11. REFERENCES

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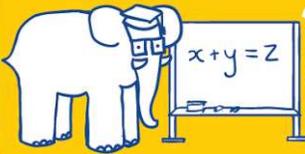
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APPENDIX 1.



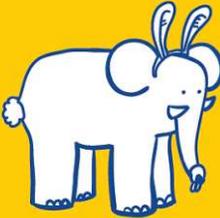
The Ele and his helper boffins from the University of East London would like to know more about how we use Elefriends to help us manage our mental health.



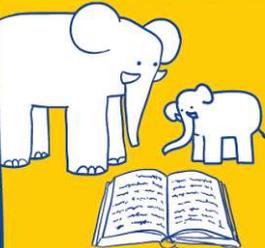
He's looking for some elefriends to volunteer to share with us what they post over a period of up to three months.



When you next login, you'll see a message explaining how you can volunteer. If you want to get involved, click, "Count me in".



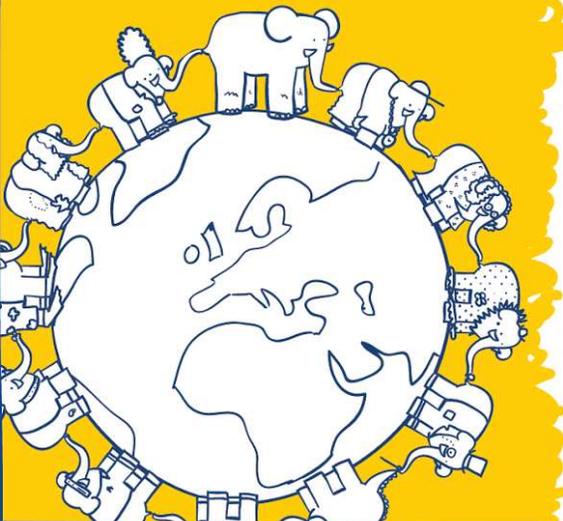
Everything will be completely anonymised, and your private information won't be shared



You'll be sent all the information about the project to keep, and the Ele will be here every step of the way.

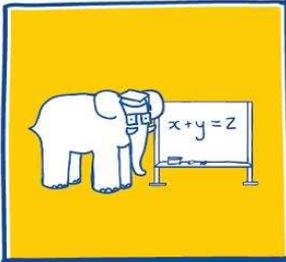


The Ele will also be chatting to some of his friends, in person or via video chat, about how they use Elefriends.



Your contributions will help us tell the world why places like Elefriends should exist... and tell the bigwigs why eles helping eles is something they should support.

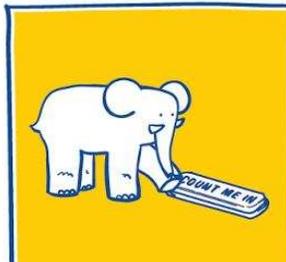




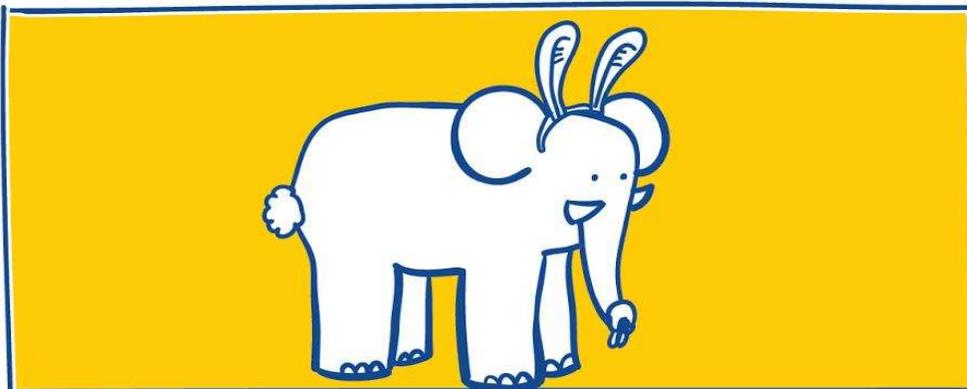
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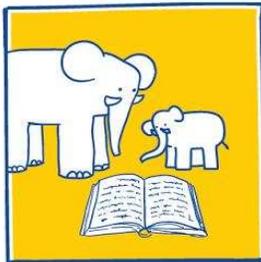
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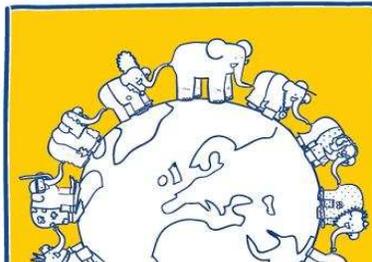
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to be a valuable source of peer support. Other instances echo this, with remarks such as having made "friends for life". The data illustrates a clear sense of community between Elefriends users, the community caring for each other, and sometimes becoming quite attached to both other users and the Elefriends environment. Many users report appear to favour online over offline support, with some expressing desire that their offline environment was more like their online environment; at least with regard to supportive sites such as Elefriends. Facebook was generally not regarded as a source of support. Elefriends was favoured by people due to the ability to seek support and understanding by speaking freely and openly, in their own time, to express how they are feeling, without apology, to others who have experienced similar feelings; and without being judged or made to feel uncomfortable about expressing themselves.